Elder Care (EC) of Dane County 2002 QAPI Focus Study Report

End-of-Life Care and Participant Death

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Study Focus:
    This study was designed to answer the following questions:
1)   How adequate are current record keeping systems for documenting end-of-life (EOL) related issues and experiences?
2)   What are the EOL care needs of elders served and how successful do teams believe they were in addressing the goals relevant to these needs?
3)   What are the challenges, barriers and care dilemmas experienced in providing EOL care?
4)   What strategies might be implemented to address these challenges and barriers?

Why Selected: Rationale for Study:
    Inadequate care of the dying is emerging as a major concern in the United States among health care providers, educators, and policy makers. Although "care for those approaching death is an integral and important part of health care," far too many elders suffer from pain and other distress that practitioners could prevent or relieve, and significant gaps remain in scientific knowledge about EOL care (Field & Cassel, 1997, p. 4).   Several studies document deficiencies in care of the dying (Meier, Morrison, & Cassel, 1997).

    The shortcomings in EOL care in America, have led to the development of the "End of Life movement" (Sherman, 1999, p. 113), whereby foundations, Academic Centers, Institutes, and professional Associations are seeking to improve training, research and services in this domain.   Several National Initiatives are urgently seeking to improve practices and policies relevant to care at the end of life care, reduce barriers presented by the health care industry, and enhance professional knowledge and skills in medicine, nursing, and social work (Meier et al., 1997).   "Hospice programs represent one substantial innovation of the past quarter century that successfully addresses the care needs of some people coming to the end of life" (Lynn, 2000, p. 2509), by providing comprehensive interdisciplinary team care. Despite its advantages, however, hospice is utilized for only a short time, by a small portion of the dying population (Fox, Landrum-McNiff, Zhong, Dawson, Wu, & Lynn, 1999). As a result and "because of the restrictive regulatory climate and the interpretation of what is an appropriate disease trajectory for a hospice person, hospice seems ill-equipped to respond" to the growing numbers of elders who die from chronic diseases other than cancer (Brenner, 1999, p. 391). Given these restraints and the notable gaps in quality of care for dying persons, the Institute of Medicine has recommended that models for the care of the dying must be developed that integrate the principals of quality EOL care in all settings, that address the needs of persons dying from advanced chronic disease, and among poor and vulnerable populations.

    EC is one model of care that responds to this call. Most EC participants disenroll from the program due to their death. EOL care is therefore an essential component of the services needed by this population. The current study was undertaken because the timing is right to

examine and document how EC is responding to older adults dying from advanced chronic disease, in order to inform the development of other programs, improve services currently in place, and to determine if this model promotes EOL care. In terms of improving services currently in place, this study was intended to gather information that would provide essential recommendations to address challenges that may directly interfere with quality EOL care. This focus study for EC's QI progam was part of a larger on-going study being conducted by Dr. Kramer at EC.

Data Collected:
        This was a multi-method study making use of case records, survey data, in-depth interviews and focus groups. The data collected from each that are relevant to the current study will be described below:

1. Case Records: Case records were closely examined to determine what data were available that would allow us to document the characteristics of deaths occurring in the program. It was quickly determined that very little information was available in the case records. As such, it was determined that a survey would need to be designed in order to collect information about deaths that had occurred. The following very basic data from the charts of 84 of the most recently deceased participants retrospective from September 2002 were used to complement the survey data described below: Participant's whose social worker was not currently employed at EC were not included in the study as the social worker was a key source of data and was the lead in survey completion. The September cut-off date was selected to provide time for data analysis for the purpose of meeting the contract submission deadline for this focus study. This data is only a part of Dr. Kramer's research study at EC.
   - Demographic information (i.e., age, race, education level, marital status)
   - Enrollment dates
   - Living arrangements
   - Primary diagnoses
   - Last 30 days of case note entries
2. Survey data on 84 of the most recently deceased participants collected included:
   - Cause of death
   - Most clinically relevant diagnoses during last 6 months of life,
   - Questions about extent to which death was expected, came as a surprise, and if goals for care were focused on "comfort care"
   - Participant's primary residence during last 6 months, place of death and whether social worker believed the participant died in their preferred place
   - Conditions, issues, needs addressed by the team during the last months
   - Ratings on extent to which teams perceived they were successful in addressing goals for care relevant to needs of participant
   - Open ended question on the primary care dilemmas, barriers or challenges that the social worker experienced in providing care to the participant during their last 6 months of life
   - Open ended question on the changes the social worker would recommend for improving services and treatment in the future or for addressing the care dilemmas, barriers or challenges they and the teams were faced with

3. In-Depth Interviews with 2 administrators and 4 Focus Groups with team members (2 with nurses, 1 with nurse practitioners, and 1 with social workers) elicited data on the following:
   - Descriptions of the challenges and barriers to providing quality EOL care
   - Descriptions of the outcomes that teams try to achieve in terms of quality EOL care
   - Descriptions of recommendations for addressing the care dilemmas and barriers to quality EOL care

Data Collection Method and Sources of Data:

As noted above, a major source of data was derived from surveys on 84 of the most recently deceased participants because subjective data from recall was more reliable than with earlier deaths. To ensure greater consistency in the completion of the surveys, it was decided that we would ask the social workers to take the lead in completing the surveys with input from other team members. Social workers were asked and agreed to participate in the construction and pilot testing of the survey. All items were examined for clarity; efforts were made to reduce redundancy, and to ensure consistency in interpretation and completion of the questions. All social workers participated in a 3-hour training session to review the survey and discuss issues of reliability and validity. Training sessions reviewed protocols for completing the surveys. Each item was reviewed and questions were clarified and answered. Social workers were given clear instructions for how to involve other team members in order to optimize the quality of the data. For example, for all questions related to health status or conditions of the participants, social workers were instructed to consult with the primary nurse involved in providing care for the participant   Each of these items were identified on the survey with a "T" noted in parentheses to remind them to consult their team member. To enhance recall of information, essential information was collected from the case records and attached to the survey (see Case Records info collected above).

Although a multi-method approach to data collection was utilized, this study relied heavily on qualitative methods (e.g., open ended-responses on the survey, in-depth interviews and focus groups) for the following reasons. First, there is virtually no information about how service providers in integrated service systems are thinking about and responding to EOL needs among the elders dying from advanced chronic disease, and about the challenges, and barriers they encounter in providing care. It would be premature to make assumptions about what and how this care is provided or about how it should be improved without first understanding the experience from the perspective of care providers. Qualitative methods are ideally suited to research that is "exploratory or descriptive, that assumes the value of context and setting, and that searchers for a deeper understanding of the participants' lived experiences of the phenomenon" (Marshall & Rossman, 1994, p. 38). Second, a qualitative approach provides a rich understanding of these issues that could better inform program improvements and future program evaluation. Indeed, evaluators of the multi-million dollar SUPPORT project that failed to document any care improvements in following the EOL intervention, have recently suggested that perhaps their fundamental assumptions about what would work were flawed (Lynn et al., 2000.

All qualitative data (open-ended questions on surveys and interviews/focus groups) were transcribed verbatim into a word processor format, and summaries of transcripts were made so that incomplete portions or ambiguous data could be clarified. Interviews and focus groups were audio-taped (prior to transcription), and were verified for accuracy by listening to

the audiotapes while reading the printed transcript. The Primary Investigator (Betty Kramer, PhD) conducted all interviews and focus groups and completed the analysis. Dr. Kramer is a nationally regarded researcher.

Standards:

Given the exploratory and descriptive nature of this study, no set standards were used.

Results:

Adequacy of Current Record Keeping Systems for Documenting EOL related Issues:

After reviewing case records, it was quickly determined that there was very little information in the charts about the EOL experiences of participants. Once a participant died, they were disenrolled from the program, and no further records were entered. There was no way to even describe the most basic of information such as the cause of death, the extent to which health care wishes were carried out and honored, and the place of death.

What are the EOL care needs of elders served and how successful do teams believe they were in addressing the goals relevant to these needs?

Table 1 provides a description of the percentage of deceased participants who had various physical symptoms and needs addressed and the team's perception that they were successful in achieving goals relevant to each need. The most common EOL physical symptoms and needs of EC participants include pain (88%) and medication management (86%) and food and fluids concerns (81%). Half or more of the older adults served by EC additional have needs associated with constipation, dyspnea, skin integrity and incontinence. In 60% or more of the cases, teams rated their success in achieving goals relevant to physical symptoms and needs as very to extremely successful, with the exception of nausea and vomiting. In 55% of the cases in which nausea or vomiting were addressed, teams felt only a little to somewhat successful in achieving specified goals.

Table 1. Physical Symptoms & Needs Addressed and Perceived Success in Achieving Goals			
Physical Symptoms & Needs of Older Adult	**Need addressed during last 6 months**	**Perceived success in achieving relevant goals**	
		A Little/ Somewhat	Very/ Extremely
Pain	88%	35%	64%
Medication Management	86%	25%	74%
Food Fluids	81%	40%	60%
Incontinence	67%	37%	62%
Skin Integrity	63%	29%	71%
Dyspnea	62%	37%	66%
Constipation	50%	26%	74%
Nausea or Vomiting	29%	55%	45%

Table 2 provides a description of the percentage of deceased participants who had various psycho-social-emotional-spiritual issues and needs addressed during the last six months of life and the team's perception that they were successful in achieving goals relevant to each need. The most common needs in this domain addressed included the psychological and emotional response of the older adult (96%), spiritual beliefs (81%), grief or bereavement (75%), and depression (74%). Half or more of the older adults served by EC have needs addressed that are associated with funeral planning, agitation, and anxiety. As compared with physical symptoms, teams rated their success in achieving goals relevant to pscyo-social-emotinal-spritiual issues less favorably. Teams perceived that they were only a little to somewhat successful in addressing issues such as agitation (72%), depression (69%), and anxiety (55%).

Table 2. Psycho-Social-Emotional-Spiritual Issues and Needs Addressed and Perceived Success in Achieving Goals			
Psycho-Social-Emotional-Spiritual Issues & Needs Of Older Adult	**Need addressed during last 6 months**	**Perceived success in achieving relevant goals**	
		A Little/ Somewhat	Very/ Extremely
Psychological & Emotional Response	96%	40%	60%
Spiritual-belief, faith, hope	81%	47%	53%
Grief or bereavement	75%	43%	57%
Depression	74%	69%	31%
Anxiety	69%	55%	45%
Agitation	57%	72%	28%
Funeral Planning	54%	35%	65%
Cultural Beliefs & Rituals	36%	44%	56%

Table 3 provides a description of the percentage of deceased participants who had various familial and support systems issues and needs addressed during the last six months of life and the team's perception that they were successful in achieving goals relevant to each need. Not surprisingly the psychological and emotional response of family members and the issue of supporting caregivers was a need addressed during the last six months of life for the vase majority of participants (95% and 94% respectively). Personal care respite and coordination with facilities were also very common needs addressed. Teams rated their success in achieving goals relevant to these needs very highly, with the exception of family conflict. Family conflict was present in 59% of the cases. In 63% of these families, teams reported that they were only a little to somewhat successful in achieving goals relevant to family conflict.

Table 3. Familial and Support System Issues and Needs Addressed and Perceived Success in Achieving Goals			
Familial and Support Systems Issues & Needs	**Need Addressed During Last 6 Months**	**Perceived Success in Achieving Relevant Goals**	
		A Little/ Somewhat	**Very/ Extremely**
Psych & Emotional Response of Family	95%	28%	72%
Caregiver/Support System Involvement	94%	28%	72%
Personal Care Respite	86%	21%	79%
Coordination with Facility	71%	11%	89%
Family Conflict	59%	63%	37%

What are the challenges, barriers and care dilemmas experienced in providing EOL care?

The open ended questions from the survey data, the in-depth interviews and the focus group data revealed very rich descriptions of a wide variety of challenges, barriers and care dilemmas. This data was categorized into six primary domains, each of which has several sub categories. The primary domains and subcategories are briefly noted in Table 4. A more detailed description of each of these with accompanying examples is provided in the Appendix. The challenges, barriers and care dilemmas were those that were related to the characteristics and needs of participants themselves. These included the challenges of caring for persons with long-standing mental health issues, or those with cognitive impairments. It included the challenges of managing difficult to control symptoms and the older persons personal response to their health problems. The nature of health conditions sometimes distracted teams from the EOL issues that might otherwise be addressed (e.g., focusing on acute care needs such as an amputation). Incapacities of support systems were frequently mentioned and may reflect the many challenges of helping elders who are poor and who have complex family situations or no family at all. A great deal of attention was given to the challenges associated with care preferences and advanced directives that are often difficult to elicit, are complicated by multiple players perceptions of what should be done, and are often difficult to implement given the support system insufficiencies. Transitions to other health care systems commonly occur at the EOL among this population. For example, although 57% of EC participants reside in a family care home during their last six months of life, only 17% die there. The challenges associated with transition have serious consequences for participants. Finally, for participants for whom English was not their primary language, cultural and language barriers included distrust, problems of interpretation, and incongruent support systems (e.g. living arrangements that are not culturally congruent.

Table 4. Challenges, Barriers and Care Dilemmas Experienced in Providing EOL Care

Characteristics and Needs of Participants
- Enduring Characteristics
- Recently Developed Characteristics
- Medical Management
- Personal Response to the Situation
- Missed EOL

Incapacity of Support Systems
- Unavailability
- Unwillingness
- External Demands
- Frailities
- Addictions
- Conflict
    i. Enduring Family Conflict
    ii. Situational
    iii. Family members hostility/anger
- Past promise

Care Preferences and Advanced Directives
- Incongruent perceptions
- Unclear/unknown preferences
- Inconsistent preferences
- Preferences difficult to implement (see "incapacities of support systems")
- Team's discomfort

Transitions to other health Care Systems
    Transitions with Team's Awareness
- Acceptance
- Refusals

    Transitions without Team's Awareness
- Dumping

Consequences of Transitions
    Transitions with Team's Awareness
- Lose Palliative Care
- Missed Diagnoses

    Transitions without Team's Awareness
- Wishes and/or care plan not enacted

Cultural and Language Barriers:
- Distrust
- Interpreters
- Incongruent Support Systems

<u>What strategies might be implemented to address these challenges and barriers?</u>

A great many recommendations were uncovered for addressing challenges and barriers confronted in providing EOL care. These were categorized according to the challenges that they were relevant to. Table 5 lists the primary recommendations identified. A more detailed description of these recommendations, along with examples is provided in the Appendix.

Table 5. Recommendations for Addressing the Challenges, Barriers and Care Dilemmas Experienced in Providing EOL Care

Characteristics and Needs of Participants
- Acceptance
- Assessment

Incapacity of Support Systems
- Aggressively Address Quality of Care Concerns
- Enhance Availability of Support Systems
- Enhance Communication to Minimize Family Conflict
- Acceptance

Care Preferences and Advanced Directives
- Routinize & Normalize EOL Care Planning
- Enhance Communication

Transitions to other health Care Systems
- Make Efforts to Minimize Transitions
- Be Proactive
- Aggressive Advocacy

Cultural and Language Barriers:
- Enhance Cultural Competence

Limitations of the Study:

The limitations of this study temper the conclusions that may be drawn. Primary limitations of this study include its reliance upon self-reported and subjective recall data, and its cross sectional design. The accuracy of the data was dependent on complete and honest responses by team members, and their ability to accurately recall information from deaths that had occurred in the past. To address this concern we provided case note and records for the last 30 days to facilitate recall, and we eliminated surveys in which team members felt that they could not accurately recall information. The cross sectional nature of the study did not provide opportunity to follow care and care plans over time and gather data that would more fully clarify the issues and needs addressed, the goals achieved and the challenges and barriers confronted.

The population of frail older adults served by EC and the challenges facing the EC teams may be unique. The sample was non-random and consisted of those most recently

deceased. The resource and support issues facing these elders and their family members may be different in urban areas or other settings creating even greater challenges. As such results should not be generalized to all settings. Never the less, this study suggests that even amidst a resource rich program that offers integrated funding to address complex health and social problems of elders, that there are significant challenges and barriers to providing quality EOL care.

What Would We Do Differently?

Given the lack of information available to us, and the exploratory nature of this study, we believe that the methods were appropriate and revealed valuable information relevant to our study questions. Learning about the problems with the documentation system, afforded opportunity to enhance record keeping. Thus future research will benefit from this.

Next Steps:

Findings from this study have already been presented to and validated by the EC staff and administration and will next be shared with the Board of Directors.

Findings from this study suggest that there are many barriers and challenges that derail quality EOL care that are associated with the transitions that occur near the EOL. For our next QI study, we intend to study transition more carefully. We will examine the deaths which occurred in the last six months of 2002 and the first six months of 2003 to determine what transitions occur, to what setting, and whether the participants health care wishes were followed. Findings on ICU utilization will be compared with data from the "Means To A Better End: A Report on Dying In America Today" funded by Last Acts and the Robert Wood Johnson foundation.

This project was part of a larger study, funded by the John A. Hartford foundation focusing on the phenomenon of EOL care in the EC program. Given the important findings about the prevalence and challenge of addressing family issues at the EOL, the PI Betty Kramer, intends to collect additional information from in-depth interviews with older adults and their family members to examine their perceived needs and wishes for EOL care, and their experience of family conflict.

How Will the Findings Impact Care at EC?

EC has already made changes to how EOL information will be documented. During this study a Disenrollment Summary was created as a contact type in PRIME, the software documentation product used by Partnership). Guidelines were created and staff training was held. In December 2002 another contact type titled Health Care Wishes was created in PRIME to denote team member narrative notes on EOL issues. Staff were trained in January 2003. These procedures should greatly enhance the documentation of EOL issues and make the notes more accessible and easier to retrieve.
The EC EOL Committee will consider the findings and recommendations and determine how to best meet the needs identified. These findings including the issues team members felt less

successful in addressing will be considered in developing training programs and providing resources for the teams. Further studies will explore transitions to other care settings during the last six months of life.

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**Challenges, Barriers and Care Dilemmas that Derail Quality End-of-Life Care
for Low-Income Elders with Advanced Chronic Disease**

CHARACTERISTICS AND NEEDS OF PARTICIPANTS:

Enduring Characteristics:
- Mental health problems (e.g., depression, personality disorders, limited insight)
- Communication preferences and styles (e.g., private nature, communicates little, does not communicate feelings, difficult to engage in EOL discussions)
- Beliefs (e.g., believes one should not dwell on difficult issues, outsiders are not to be trusted)
- Behaviors (e.g., inappropriately affectionate with females and team members)

Recently Developed Characteristics:
- Cognitive impairments (e.g., dementia, unable to answer health related questions, or engage in discussions about wishes, questionable capacity and aphasia)
- Problem behaviors (e.g., behaviors associated with dementia precipitated many housing changes which escalated symptoms and confusion)

Medical Management:
- Difficult to control symptoms (e.g., pain, depression, anxiety)

Personal response to situation:
- Limited acceptance of health decline
- Emotional distress at the EOL (e.g., increased anxiety and decreased mental status during last 6 months, older adult in constant state of despair and fear that did not respond to interventions; older adult's feelings of loss were pervasive and difficult to ease, anger directed at team)

Missed EOL:
- Unexpected death (e.g., unexpected death didn't allow time for planning and interventions, team focused on other health care problems and lost sight and didn't anticipate death and other EOL care needs)
- Medical needs complicated and difficult to diagnose and treat (e.g., some diseases not diagnosed until end stages)

INCAPACITY OF SUPPORT SYSTEMS:

Unavailability
- Minimal supports available (e.g., no family, older adult alone, absent or limited family involvement with older adult and/or with team)
- Caregiver incarcerated (e.g., needed to advocate for early release of daughter from prison to stay with older adult at night)

- Challenge to find overnight care and supervision in the home (e.g., caregiver shortage limits availability of quality care providers)

Unwillingness:
- Support systems fail to "partner" with the team (e.g., family does not inform team of changes in condition, and/or does not follow agreed upon care plan)
- Difficulty following through with pre funeral planning (e.g., one daughter did not follow plans to contact local funeral home for arrangements, plans were eventually taken over by out of state family and the body was taken to another state for burial).

External Demands:
- Limited family resources (e.g., daughter working two jobs and leaving children with critically ill older adult, unable to ensure older adult was getting care she needed)
- Difficulty engaging in discussions about EOL care and Advanced directives

Frailties:
- Caregiver unable to provide care necessary to allow older adult to be in their preferred setting (e.g., frail spousal caregiver)

Addictions:
- Caregiver substance abuse and history of drug addiction within family (e.g., ingesting pain meds rather than giving to care receiver)

Conflict:
- Enduring family conflict (e.g., long standing disagreements, history of homicide, violence, and/or extreme family conflict)
- Situational specific family conflict (e.g., regarding health status and care preferences, see below)
- Family members hostility/anger directed toward older adult and/or in-home care workers

Past Promise:
- Unrealistic expectations of family (e.g., want older adult to remain in their own home because they promised never to place them in a facility, yet 24 hour care is necessary and/or unavailable in the home)

CARE PREFERENCES AND ADVANCED DIRECTIVES

Incongruent Perceptions:
- Disparity between participant and family regarding acceptance of impending death (e.g., older adult's ability to accept her dying was made difficult by son's fear and push to "do more")
- Disagreements and conflicts in health status perceptions and care preferences (e.g., outright disputes between POA-HC and other relatives about plan for care; challenge to find consensus on perceptions of health status, and what measures older adult and family want to pursue)
- Convergence near time of death (e.g., distant family members appear as death draws near, experience of family conflict often escalates; team members have had little opportunity to establish relationships with these family members who commonly question the care plan, and have different perceptions about what should be done)

Unclear/Unknown Preferences

- Communication barriers limit understanding of care preferences and wishes (e.g., cognitive impairments, language barriers, challenge to empower older adult to make her wishes known and getting spouse to accept older adult's wishes for EOL care)
- Ambiguous wishes (e.g., older adult requested and signed a DNR order, later expressed more of a do everything philosophy, but wanted to keep the DNR order in chart)

Inconsistent Preferences

- Fluctuations in care preferences (e.g., with fluctuations in health status older adults and family members become less certain about what they want; caregivers vacillate on acceptance of comfort care vs. treatment)
- Older adult does things to please family rather than meeting their own needs and wishes

Preferences Difficult to Implement

- See "Incapacities of Support Systems"

Team's Discomfort

- Perceptions of high risk (e.g., Challenge to honor older adult's wishes when they are accompanied by many risks; level of care needs exceed ability to honor wishes person too ill to be transported to die in preferred setting)
- Perceptions of high cost (e.g., 24 hour care in home too costly; needs could be met in other setting for less cost)

TRANSITIONS TO OTHER HEALTH CARE SYSTEMS

Transitions with team's awareness
   <u>Acceptance</u>

- Challenge to discuss and prepare older adult and family to accept transition to other settings (e.g., skilled nursing)
   <u>Refusals</u>
- Optimal placement sites refused transition (e.g., nursing home facility refused to contract with agency so older adult had to be moved to new setting, nursing homes refuse to accept older adults for EOL care)
- Other health care providers refusing to partner with team (e.g., failure to share critical information, not agreeing to follow care plan)

Transitions without team's awareness
   <u>Dumping</u>

- CBRF and NH staff unnecessarily transfer older adult to hospital (e.g., staff verbalize discomfort with EOL care and feel inadequate to address critical issues that surface at EOL)

CONSEQUENCES OF TRANSITIONS:

Transitions with team's awareness
Lose Palliative Care:
- CBRF and/or nursing home unwilling and/or unskilled in providing "comfort care" and quality EOL care: (e.g., uncooperative staff, staff fail to inform team of health changes, fail to follow through on simple requests for comfort measures, seem highly unskilled for providing "comfort care", fail to follow through on care plan resulting in respiratory distress and great emotional stress for spouse)
- Hospital focuses on active treatment when not indicated (e.g., ordering unnecessary tests; team actually had to yell at hospital M.D. to get them to stop ordering unnecessary tests and therapies for woman with advanced cancer)
- Hospital lack of timely treatment for comfort (e.g., did not provide pain meds until team insisted)
Missed Diagnosis
- Appropriate assessments not completed (e.g., advanced terminal disease not detected by ER staff because they did not remove older adult from w/c to complete x-rays which would have revealed multiple fractures resulting from multiple myeloma)

Transitions without team's awareness
Wishes and/or Care Plan Not Enacted
- Failure of CBRF staff to follow DNR order (e.g., didn't put DNR bracelet on in time and older adult received CPR)
- Team unable to advocate for older adult, assist in their care, or enact care plan at EOL due to communication breakdown during transition (e.g., hospital or family fail to notify team that older adult was admitted to hospital; left message on social worker's machine but she was away; team saw obituary)

CULTURE AND LANGUAGE BARRIERS

Distrust
- Cultural distrust of white team (e.g., family members saw EOL comfort care as racially motivated to end older adult's life even though older adult was in agreement)
- Misperceptions about treatment
Interpreters
- Communication through interpreters less complete (e.g., one woman who had been able to engage in conversations with the team, began speaking in her native tongue as her health declined; the communication with the interpreter was less revealing than prior conversations
- Limits to confidentiality through use of interpreters who are known to participant strain communication
Incongruent Support Systems
- Living arrangements not culturally congruent (e.g., NH, CBRF)

Recommendations for Addressing Challenges, Barriers, and Care Dilemmas that Serve to Derail Quality End-of-Life Care for Older Adults

CHARACTERISTICS AND NEEDS OF PARTICIPANTS:

Acceptance
- Recognize and accept what can and cannot be changed
- Understand that some life choices and old hurts will follow people to the grave

Assessment
- Earlier assessment for capacity
- Discuss EOL wishes as a regular part of assessment (for all participants irregardless of health status)

INCAPACITY OF SUPPORT SYSTEMS:

Aggressively Address Quality of Care Concerns
- Conduct pre-placement education and training with CBRF or other care providers (i.e., what to expect, assess staff capability to manage pain, comfort and methods for providing palliative care for residents)
- Continue at admin level to work with CBRFs with quality concerns
- Advocate for EOL care training for ER employees, NH employees, CBRF employees
- Continue to educate facilities about ECP services and expectations
- Proactively include MD as needed to facilitate clear discussions with older adult and family members to ensure MD is on board with wishes
- Use facilities with proven track record to ensure quality (bring in ECP managers for assistance)

Enhance Availability of Support Systems
- Identify alternatives for quality care for dementia specific CBRF
- Enhance pool of respite providers
- Expand number of facility contracts
- Consider ECP owned and operated assisted living facility

Enhance Communication to Minimize Family Conflict:
- Have family meeting early to improve communication and help family discuss participant's health, quality of life and ongoing care sooner while still healthy
- Communicate with family earlier on
- Consider collateral providers as a resource (e.g., hospice, other family) to offer "unbiased" objective support and education
- Involve physicians in EOL comfort care discussions to clarify health care status with family

Acceptance
- Recognize and accept what can and can not be changed
- There may not be much the team can do to eliminate long-standing family conflict
- Sometimes conflicts need to play out

CARE PREFERENCES AND ADVANCED DIRECTIVES:

Routinize & Normalize EOL Care Planning
- Routinely address with all participants
- Directly address issues over and above DNR status (attend to preferences, funeral planning)

Enhance Communication:
- Engage in more EOL discussions with participants
- Involve physicians in EOL comfort care discussions/decisions with family
- Consider alternative and multiple techniques to help older adults express EOL care wishes
- Have at least one family meeting to discuss issues of importance
- Have many family meetings as soon as issues arise
- Draw family members and friends into discussions to facilitate comfort and recall of wishes
- Take initiative to make EOL discussion less intimidating with primary caregiver; be at ease and convey personal comfort with the topic

TRANSITIONS TO OTHER HEALTH CARE SYSTEMS:

Make Efforts to Minimize Transitions
- Use geriatric psych unit to prevent unnecessary placements (e.g., when behaviors are escalating)
- Routinely use stickers on front of client charts in facilities to provide contact info and directions for emergencies
- Enhance EOL care training and communication with care providers (formal and informal) to prevent unnecessary transitions
- Ensure that EOL care wishes and strategies for handling likely health care emergencies are known by all care providers
- Nurture trusting relationships with key care providers

Be Proactive
- Get DNR bracelets routinely and early on
- Ensure that bracelets are worn and DNR status is well documented
- Discuss health care wishes routinely so wishes are known and documented well in advance by all involved

Aggressive Advocacy
- Continue to aggressively advocate for "comfort care" with health care providers who focus on active treatment or fail to provide compassionate quality care
- Clearly communicate concerns to misinformed health care providers and inform supervisors when necessary to minimize substandard care

CULTURE AND LANGUAGE BARRIERS:

Enhance Cultural Competence
- Elicit a deeper insight into cultural supports and connections
- Identify other interpreters outside the home and community
- Find ways to tap more deeply into the cultural community (e.g., consult with tribal leaders)
- Seek more insight into family's cultural perspective (e.g., consult with Hispanic community leader to act as mediator/facilitate discussion)
- Seek to understand cultural beliefs as related to EOL care
- Be willing to work with the family more than is tradition in our culture (e.g., accept that primary communication may not be with older adult)

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Recommendations for Addressing Challenges, Barriers, and Care Dilemmas
At the End-of-Life for Low-Income Elders with Advanced Chronic Disease

THE NATURE OF ADVANCED CHRONIC DISEASE: Blending care for the living and the dying

Maintain a Panoramic View
- When one aspect of participant's health dominates focus of care, shift focus to comprehend larger scope of situation and consider other supportive interventions (i.e., do not let acute medical crises take away from the "bigger picture").

Routinize & Normalize EOL Care Planning
- Make EOL discussion more mainstream in comprehensive treatment and case management services, therefore making conversations with participant or primary caregiver less intimidating and subsequently more productive.
- Routinely address EOL care preferences with all participants as early as possible, including issues over and above DNR status (e.g., health maintenance, diagnostic testing, tube feeding, hospitalization, burial wishes, and funeral planning).
- Conduct at least one EOL care planning meeting (i.e., with family, elder, and health care agent) regardless of participant's health status.
- Infuse palliative care principles throughout treatment and case management services (e.g., initiate comfort care plan sooner).

CHARACTERISTICS AND NEEDS OF PARTICIPANTS

Employ Unique Interventions for Persons with Dementia at EOL
- Maintain ongoing assessment for capacity.
- Develop creative interventions to allow for grief expression, despite cognitive loss (e.g., art, music, or validation therapy strategies).
- Individualize and modify therapeutic approaches to address new symptoms and stages of the illness.
- Elicit EOL information (personal wishes/beliefs) in early stages of memory loss.
- Draw in family/friends to facilitate comfort and possible recall during EOL discussions. Ask family members about other family deaths to elicit general attitudes/beliefs on the subject.

Utilize the Therapeutic Relationship in the Face of Emotional Distress
- Identify and use strengths of team members to make inroads at EOL. Be flexible in approach and roles.
- Use one team member as the primary contact if necessary; develop a close relationship and use it in as many situations as possible. Build on any special history or connection to participant and/or family.
- Involve adult children where possible to facilitate a partnership. Identify a family member or friend who "carries the most weight" with the participant.

Recognize What Can and Cannot be Changed: "The Wisdom to Know the Difference"
- Recognize and accept what can and cannot be changed.
- Accept that conflicts may need to play out.
- Accept that some life choices and old hurts may "follow people to the grave."

CHARACTERISTICS AND COMPETING NEEDS OF THE FAMILY SYSTEM:

Create an Arena for Healthy Conflict: The Family Meeting
- Facilitate family meetings early to discuss participant's health, quality of life, placement, diagnosis, prognosis and ongoing care even when relatively healthy. Include family other than spouse if and when possible to maximize involvement.
- Have repeated family meetings when situation intensifies to facilitate decision-making and understanding of care options and outcomes.
- Identify a key player (family member, daughter, POA, guardian, etc.) who is willing to work cooperatively with the team.
- Meet the family where they are at in terms of conflict, acceptance of their loved one's health decline, and mental health and well being by providing a nonjudgmental and supportive environment.
- Utilize events related to changes in health status (e.g., hospitalizations, new diagnoses) to facilitate discussions around EOL care preferences.

Punctuate Education to Maximize Family Absorption of the EOL Process
- Break EOL discussions into 3-4 meetings to educate and to give an opportunity to absorb. Family members can contemplate what they have heard, generate questions, and meet again to discuss.
- Help family step-by-step to anticipate the changes that they can expect to see while shifting gears from routine to EOL care. Be up front with the realities of the elder's condition (e.g., psychological symptoms or changes they might see when the participant has been struggling with psychosis and psych meds may be discontinued for comfort care).
- Consider collateral providers as a resource (e.g., hospice, other family) to offer "unbiased" objective support and education.

Recognize What Can and Cannot be Changed: "The Wisdom to Know the Difference"
- Accept that family conflicts may need to play out.
- Delineate between situational specific conflict and lifelong patterns of conflict.
- Accept various levels of involvement. Allow some family members to gracefully refuse their role in situations that make them uncomfortable.

INCAPACITY OF SUPPORT SYSTEMS

Infuse Palliative Care throughout HealthCare Settings
- Demand the ability to use comfort care measures in various care settings, such as continuous pain medication for pain management.
- Advocate for option of having a private room in nursing home at the EOL.
- Modify policies to financially support palliative care in all settings.
- Encourage "dying in place " (i.e., continuity of living environment) when possible to minimize distress

Aggressively Address Quality of Care Concerns
- Conduct preplacement education and training with CBRF staff or other care providers to enhance competence in EOL care (i.e., assess staff capability to manage pain and ensure comfort and facility methods for providing palliative care for residents).
- Develop administrative structures to work with CBRFs with quality concerns. Use facilities with a proven track record to ensure quality.
- Screen physician panel for EOL and geriatric skills. Conduct a panel orientation about comfort care with physicians to enhance competence in EOL care.
- Offer resources to support all providers, from front line workers to physicians, to deal with personal responses to EOL.

Enhance Availability of Resources/Supports
- Expand number of contracted facilities that partner with the ElderCare Program.
- Enhance pool of affordable respite providers, especially in rural areas. Collaborate with other EOL care providers (e.g., Hospice) to maximize use of available respite resources and coverage.
- Seek and create better options for placements: especially dementia specific CBRFs, placements for people with infectious illnesses such as MRSA.
- Advocate for additional funding for in-home care at all policy levels. Increase home visits by on call staff to support caregiver.

Imbibe Support Systems into the Team Model
- Continue to educate facilities about ECP services and expectations and to develop protocols for the sharing of pertinent information between staff and team. Likewise, make efforts to understand the role of social services in the facility setting.
- Emphasize family and facility needs to inform team of ER and hospital visits.
- Identify key person (family member, NH social worker, daughter, POA, etc.) to work cooperatively with team.
- Meet with facility staff prior to EOL to give clear directions regarding participant's wishes for EOL care.

HONORING CARE PREFERENCES AND ADVANCED DIRECTIVES

Ignite the Conversation
- Initiate rapport building and discussions about health care wishes early.
- Increase the frequency of EOL conversations.
- Encourage conversations by including health care agents and as many family members as possible or as many as participant will allow.

Build Bridges to Enhance Communication
- Use providers to serve as bridges between team and families, e.g., proactively include MD as needed to facilitate clear discussions with older adult and family members.
- Serve as a liaison between providers and families, e.g., by initiating and facilitating discussions between family and hospital physicians and supporting family in relaying their wishes to medical staff.
- Consider collateral providers as a resource (e.g., hospice, other family) to offer "unbiased" objective support and education when the participant's and family's wishes are in opposition.

Articulate Clear and Specific Wishes
- Develop techniques for helping elders express themselves, talk about the future, and express their wishes for EOL care (e.g., using reminiscence to guide the elder from safe, concrete topics into abstract topics such as defining quality of life, using thought provoking questions to elicit beliefs about the afterlife, funeral/burial wishes, and offering supportive listening).
- Educate individuals about the variety of choices they have and the consequences of each to negate decisions based solely on family opinion, religion, and/or cultural beliefs.

Anticipate Ethical Dilemmas
- Develop protocol for honoring a participant's goals and wishes despite the fact that they may not be "medically ideal".
- Send ethical dilemmas to the ethics committee early on.
- Familiarize staff with the legal pathways for protecting participants from family who do not have their best interest at heart.

Punctuate Education to Facilitate Acceptance (See above)

TRANSITIONS TO OTHER HEALTH CARE SYSTEMS

Prevent Unnecessary Transitions
- Identify the most appropriate placement sooner (e.g., geriatric psych unit when behaviors are escalating, to prevent other unnecessary transitions).
- Apply stickers to client charts in facilities to provide contact information and directions for emergencies.
- Enhance formal and informal EOL care training and communication with care providers to minimize discomfort or panic related to caring for the dying.

Aggressive Advocacy
- Aggressively advocate for comfort with health care providers who focus on active treatment or fail to provide compassionate quality care.
- Clearly communicate concerns to misinformed health care providers and inform supervisors when necessary to minimize substandard care.
- Be vigilant when transitions occur to inform other health care providers of the participant's wishes.

Ease the Transition
- Reframe language to lessen stigma about care settings (e.g., instead of "nursing home" use "skilled nursing" or "rehabilitation" or "convalescent" center; instead of CBRF, use "assisted living", instead of "day center", use "life transition center")
- Provide realistic information about services provided in care settings
- Encourage "trial" periods (e.g., use facility for respite to "test it out")
- Work aggressively with facility staff prior to, during and following transitions (e.g., meet to share information that will facilitate knowledge of elder and ease transition, call to see how things are going, meet with staff)

CULTURE AND LANGUAGE BARRIERS

Reconcile Dissonance between "Patient-Centered Care" and Less Individualistic Cultures
- Be willing to work with the family more than is tradition in "mainstream" culture (e.g., accept that primary communication may not be with older adult).

Seek Out Cultural Liaisons
- Consult with Hispanic community leader to act as mediator/facilitate discussion to empower family members to speak out.
- Consult with Native American tribal leaders to tap more deeply into the cultural community.
- Have an intermediary from the Hmong community help bridge the gap between cultures.
- Identify other interpreters outside the home and community

Enhance Cultural Competence
- Elicit a deeper insight into the elder and family's cultural perspective, supports, and/or connections.
- Clarify cultural beliefs as related to EOL care, and professional trust.
- Increase knowledge of cultural community resources.
- Use collateral sources of information to understand optimal ways of working with elder and family (e.g., prior assessments and experience of other professionals, written information)